

Good afternoon, my name is Marta. This is my daughter Caroline and we live in Virginia.

Caroline is 7 years old, but she can't walk, talk, use her hands, sit unassisted, or even chew her food because she has Rett Syndrome – a neurological disorder that interferes with her ability to control her body. Caroline is essentially trapped inside her body. But she's so smart and so full of life and full of love. She's obsessed with Beauty and the Beast, she is thriving in school, and she loves being with her friends.

Caroline didn't start showing symptoms until after she turned 1, when she still wasn't walking or even crawling. But she could say about a dozen words and she could feed herself. The around 14 months, she started having involuntary and constant hand movements – which is a hallmark of her disorder. She also started choking on her food, she could no longer get her words out, and she struggled to hold on to her toys. Her hands stopped working almost overnight.

My husband and I received the official diagnosis when she was 17 months old.

We were stunned and completely devastated. But we promised her that we would live a happy and full life no matter what.

I never imagined that I would have a child who would depend on us for every aspect of daily living for the rest of her life. And I certainly never imagined I would have a child who would rely so much on a government program like Medicaid.

Caroline is the bravest person I know. She endures a level of discomfort and pain that is unimaginable to most of us in this room. She takes a total of 10 different medications a several times a day to manage a long list of medical complications. She suffers from seizures and she is susceptible to respiratory failure and pneumonia – which nearly took her life in the summer of 2015. She needs to undergo a total of a couple of hours of lung therapies every single day so that she can do something we all take for granted – to breathe and stay alive. When she has a cold (which is often), we have to administer her lung treatments almost non-stop, round the clock to keep her out of the intensive care unit.

Caring for Caroline is a full-time job and Medicaid provides skilled nursing care which allows us to raise Caroline in our home instead of a hospital or institution. This allows my husband and me to hold jobs and take care of other family needs. Medicaid also helps cover the cost of medical care and equipment not covered by our private insurance. These costs can add up to a few thousand dollars each month.

Because of the medical care we're able to administer at home and the life-saving hospital-grade medical equipment Medicaid helps cover, Caroline went from spending weeks in the ICU almost each time she caught a cold to just 1 hospitalization last year. Losing Medicaid services would be detrimental to our family. I'm not sure how my husband and I would be able to hold jobs. We would not be able to afford all of the medical care. Caroline needs which would put her life at risk and decrease the quality of her life. Our living situation would not be sustainable. Medicaid not only keeps Caroline alive – it also allows us to function as a family and continue to be productive, tax paying members of society.

The House Republican Plan for Medicaid would put my daughter's life at risk. And my family is terrified. We don't know long we have with Caroline, but we her to live with us -- in our home -- for as long as she's alive. We just want her to go to school just like every other child. We want our family to have some semblance of a normal life. We want our daughter to get what she needs to feel safe and stay alive.

The Administration and Congress need to act in the interest of the country, and that includes every member of society – children, people with disabilities, the elderly, hard-working families who can't make ends meet, and other vulnerable populations. Caroline's life is in your hands. Please do the right thing. Protect Medicaid.

Thank you.